



7202 NE Evergreen Parkway, Suite 100 Hillsboro, OR 97124-7251

> Voice: 503-693-4100 FAX: 503-693-5600 TTY: 971-673-0372

# Action Required: Newborn Bloodspot Screening Changes

November 12, 2019

Dear Medical Provider,

The Oregon State Public Health Laboratory (OSPHL) recently completed a review and revision of the Northwest Regional Newborn Screening Program (NWRNBS) Oregon Administrative Rules (OARs). The OAR revision will change the way you care for infants in your practice setting. All health care providers caring for babies born in Oregon will need to comply with the new requirements beginning November 25, 2019. Please review the information provided below and in reference documents.

### What do I need to do?

Please review the following:

- 1. Attached document detailing the Rule changes.
- 2. Updated Newborn Bloodspot Screening (NBS) Practitioner's Manual, 11th Edition, 2019.

By Oregon law, providers caring for infants in Oregon must follow both the OARs and the NBS Practitioner's Manual.

# What has changed?

The OAR changes update the:

- Definitions of terms used,
- Timing of specimen collection,
- Methods of testing, and
- Retention of residual bloodspot specimens.

The OAR change also includes edits for housekeeping and references to the Oregon Newborn Bloodspot Screening Practitioner's Manual.

The NWRNBS has provided this letter as a reference for your convenience. Please review the full Newborn Screening OAR and NBS Practitioner's Manual, 11<sup>th</sup> Edition, 2019, to ensure your practice complies with all requirements. These documents can be found at: www.bitly.com/nbs-news.

Thank you for your attention to these changes and for all you do to support Oregon families.

Sincerely,

Christianne Biggs, MS Manager, Newborn Bloodspot Screening

# Attachment:

- Oregon Newborn Bloodspot Screening Changes - November 25, 2019

# Attachment: Oregon Newborn Bloodspot Screening Changes – November 25, 2019

#### **Definitions of Terms Used**

The definition of premature has been removed due to non-use. The definition of low birth weight has also been removed.

# **Timing of Specimen Collection**

Specimen collection timing is critical for accurate newborn screening results. Based on analysis of lysosomal storage disorder testing results and discussion with contracted medical consultants over the past year, changes have been made to the timing of specimen collection for infants.

Specifically for lysosomal storage disorder testing:

- Infants weighing less than 2000 grams at birth or whose specimens were collected prior to 20 hours of life will require recollection to obtain accurate results. For most births this will occur with the routine second screen collection unless the Program requests another specimen.
- These infants will not need a three-part kit unless they are admitted to the NICU.
- The timing of specimen collection is based on birth weight, not based on the infant's weight at the time of final specimen collection.

Please note that it is critical to ensure the baby's birth weight and date and time of collection are accurate in for this testing.

Babies admitted to the NICU will still require a three-part kit, regardless of birth weight.

The following is a table showing the age of infant at specimen collection:

	Collection Kit	First specimen	Second specimen	Third specimen
Routine Birth	Double Kit	As soon as possible after 24 hours of age but before 48 hours of age	10-14 days	Not Collected
NICU infants transfused prior to 24 hours of age	Triple Kit	Prior to transfusion	48-72 hours after birth	~ 1 month, no sooner than 28 days
NICU infants <b>not</b> transfused prior to 24 hours of age	Triple Kit	As soon as possible after 24 hours of age but before 36 hours of age and prior to transfusion	10-14 days of age (11- 15 days of life)	~ 1 month, no sooner than 28 days

## **Methods of Testing**

In OAR 333-024-1070(6) the method fluorescent immunoassay has been added to Biotinidase deficiency.

### **Retention of Residual Bloodspot Specimens**

In OAR 333-024-1090 retention time for specimens has been changed from one year to 18 months.